



Gluten Free and Casein Free Diets for Autistic Spectrum Disorders - Your Questions Answered.

This guide has been produced by NHS Highland, for parents and carers of children with an Autistic Spectrum Disorder. The questions are commonly asked by parents in their consultations with health professionals.

Some parents of Autistic children have reported improvements in their child's development after removing gluten or casein. Other parents have tried to remove gluten or casein but not seen any improvements.

We hope that the answers given to these questions will help parents, carers and children decide whether a gluten free or casein free diet is worth considering for their child. We also hope the information that follows help to ensure that this diet can be implemented as safely and effectively as possible.

What are gluten and casein?

Gluten is a protein found in wheat, oats, barley and rye. It is not found in other starchy foods like corn, rice and potatoes.

Casein is a protein that is found in milk and milk products.

Why might gluten and casein cause a problem?

Some researchers have suggested that a proportion of children with Autism are addicted to gluten or casein. It is thought that they might be partly digested in the gut to peptides that make their way into the brain where they act like the drug morphine.

Some of the characteristic symptoms of Autism loosely resemble the effects of morphine and other similar drugs.

What improvements can be expected?

Some parents have reported improvements in attention and concentration; sleeping patterns, calmness; and, more rarely, improvements in eating habits, communication and co-ordination.

Could removing gluten or casein stop my child being Autistic?

No. There is no suggestion that gluten or casein can cause Autism. Also, Autism will **not** be cured if gluten or casein are removed. But it may be that some children behave and think in a less Autistic way if gluten or casein are removed from the diet.

How much evidence is there that gluten and casein free diets help?

There have been several studies carried out to see if gluten or casein free diets can really help reduce Autistic symptoms. Several of them suggest that it might make a difference for some children. Unfortunately, most of these studies are poorly controlled, so it is difficult to be sure that the improvements really were due to the diet. There has been one study that was quite well controlled and showed a reduction in Autistic traits among children on the diet (Knivsberg *et al*, 2002). This improvement was not seen in children in a "control group" who were not put on the diet. This study used only a small number of children for whom a problem with gluten or casein was already suspected. We do not know how representative they are of Autistic children in general.

What percentage of children with an Autistic Spectrum Disorder might benefit from avoiding gluten or casein?

We do not know. From the evidence we have locally, it could be anywhere between 10 and 50%. Among these it may be that some are affected by gluten, some by casein, and some by both.

How will I know if my child would benefit from this diet?

The only way to be sure is to try the diet.

The most likely children to benefit are those that seem to choose large quantities of foods containing casein or gluten. For example, if a child shows an unusually strong preference for pasta, Weetabix or bread, it could be evidence that they are getting a "high" from the gluten in these foods. If a child shows an unusually strong preference for yoghurt or milk, it may be that they are getting a high from the casein. On the other hand, so many foods are based on milk or wheat, so if a child shows a strong preference for particular foods, there is a good chance it will be one based on milk or wheat anyway. Also, Autistic children are often very repetitive in their food choices because they have a preference for sameness and predictability.

According to the Autism Research Unit, the most likely children to benefit from the diet include the very young, children with self-injurious behaviour, severely autistic children, and children with a high pain tolerance.

Isn't there a urine test?

Some parents have sent urine sample off to the Autism Research Unit in Sunderland. They look for peptides in the urine and if certain peptides are at very high levels, the unit recommends a gluten or casein free diet (depending on which peptides were found in the urine). We cannot be sure that the substances they are finding in urine samples are really from gluten or casein. This means we cannot recommend the test. What we can say is that testing urine is a safe and non-invasive procedure. It may be that there will be more evidence of the accuracy of urine testing in the future.

Is it safe to remove casein and gluten from the diet?

Milk products provide valuable minerals like calcium and magnesium. They also provide protein. Gluten containing foods can be good sources of fibre. In particular, wholemeal bread, oatcakes and high fibre breakfast cereals contain lots of fibre. This can help prevent constipation. All of these foods also contain energy. Therefore if gluten and casein containing foods are removed, it is important to replace the calcium, magnesium, fibre and energy with other foods. This can be a bit risky if the child eats nothing but gluten and casein containing foods. On the other hand, once a child is used to not having these foods, they might start to accept other foods that they previously rejected.

Which foods contain fibre, magnesium and calcium without containing gluten or casein?

Fibre comes from fruit, vegetables, salad, nuts, seeds, pulses, beans, brown rice and high fibre gluten free breads and breakfast cereals.

Calcium rich foods include: Fortified soya milk and soya products, tortilla chips, spinach, canned sardines, salmon or pilchards and almonds. Also, white bread is high in calcium but is not suitable for a gluten free diet.

Magnesium rich foods include brazil nuts, almonds, pumpkin seeds, sunflower seeds, peanuts, peanut butter, cashews, chick peas, split peas, popadoms, pistachios, liquorice, prawns, tortilla chips, rice and popcorn. Generally these foods contain as much or more magnesium in one portion than in a glass of milk.

Should I try gluten free and casein free at the same time?

It is often easier to start with one first. Generally, unless you specifically think gluten is the problem, start with a milk free trial. Milk free diets are usually easier and cheaper than gluten free, and it only takes 6 weeks for you to find out if it is working. Gluten free diets can take 6 months to be fully effective. Also, if you do them both at the same time and start to see improvements after a few weeks, you may not know if this because of the casein or gluten.

I am considering other diet therapies and behavioural programmes for my child. Should I introduce a gluten or casein free diet at the same time?

No. Resist the temptation to do everything at once. If you try a range of treatments at the same time, you will not know which is one is having the effect that you observe.

Can I get gluten free food on prescription?

Unfortunately, gluten free foods are not prescribable for Autism. This may change if we get more good quality research showing gluten free diets are helpful. Gluten free bread, biscuits, pasta and cakes are all available, but they are expensive. Remember

that potatoes, rice, corn, peas, beans, pulses, nuts, fruit, vegetables, salad, meat and fish do not contain gluten.

How do I know if foods contain gluten or casein?

Some foods are obvious. Milk products contain casein, and bread, pasta, cakes, biscuits and crackers contain gluten. Other processed foods use milk products or a gluten containing cereal as an ingredient. Sometimes the ingredient is not even shown on the ingredients list on the packet. This means that you will inadvertently include gluten and casein in the diet from time to time without realising it. The first time parents realise is often when their child's behaviour gets worse shortly after eating the suspect food. Some manufacturers will say "milk free" or "gluten free" on the packet.

There are gluten free and milk free diet sheets available. Also, an organisation called coeliac UK produce a comprehensive list of gluten free products. Copies of this are available on short term loan from the Child Health Dietician (phone: 01463 701314, giving your name and address).

Do I need to avoid anything else?

Some researchers believe that children who react to gluten or casein, may also need to avoid two particular food additives. These are an artificial sweetener called Aspartame, and a flavour enhancer called Monosodium glutamate (MSG) which is also sometimes called "621". MSG and Aspartame may affect the brain in the same way that gluten and casein can.

What foods contain Aspartamine or MSG?

Aspartame is used in sugar free drinks and gum and also in "diet yoghurts". If it is used it will say so on the ingredients list. Surprisingly, Aspartame is used even in many of the sugar containing diluting juices and fizzy drinks along side sugar. Water, pure fruit juice, high juice squashes, Sprite and 7-up (regular version, not diet or lite) are free from Aspartame. Remember that water is the kindest drink to teeth. If your child will not drink water, make their juice a little more dilute each week until they are weaned off the sweet taste.

MSG is found in savoury processed foods. Crisp flavourings, packet soups and sauces, stock cubes, and some Chinese Take-Aways contain MSG. Ready salted

crisps do not contain MSG. Some premium stock cubes are free from MSG too. Once again, check the ingredients list. The easiest way to avoid MSG, casein or gluten, is to use less processed foods.

If my child eats gluten or casein by mistake, what will happen?

If the diet is broken, it is common to see a temporary regression lasting between 12 and 36 hours.

This could include head banging, self-biting, changes to bowel movements and hyperactivity. If you do not see this regression immediately, you may decide the diet was not needed and re-introduce gluten or casein. However, some children regress only after the gluten or casein has been put back in the diet for weeks or months.

Should I send my child to school with a packed lunch or ask the school to provide a meal?

If you are currently making packed lunches, it is best to continue with this until you have established if your child is benefiting from a milk free or gluten free diet. If you think that they are, and would like to continue with the diet, the school should be able to provide an appropriate meal. Write to the head teacher to explain what diet the child needs. If the cook is unsure what is suitable, the Area Catering Supervisor will involve the local dietician. If your child finds the dining room environment difficult, or will only eat a very limited range of foods, you may decide to continue sending a packed lunch. The extra cost of the diet will be met by the school meal service, so the standard meal price should be all you have to pay. The cook will buy in any gluten or casein free products that she needs.

I am not sure that I want to try the diet. We have so much to cope with as it is.

It is perfectly OK not to try the casein and gluten free diet. There is no guarantee it will work and it can be a difficult diet to follow properly. Given all the information, parents are best placed to decide what is right for their child. We do not wish to promote or discourage the use of gluten or casein free diets. Our intention is far more modest than this. We hope simply that it has given you enough information to decide one way or the other.

If you would like further information, ask your paediatrician.